



NPCR Education and Training Series (NETS)

Module 3: Quality Control for Central Registries

Part 5: Data Quality Management Reports

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Data Quality Management Reports



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Types of Data Quality Reports

◆ Central Registry System Reports

- Process management
- Data quality
- Internal use
- Feedback to facilities

◆ Data Quality Indicators



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Data quality reports come in all shapes, sizes, and levels of detail. The two major categories are central registry system reports and data quality indicators. Central registry system reports include both process monitoring and aggregate data quality. Central registry reports can be used internally to monitor the functions of the central registry and can be provided to the facilities submitting the case reports to inform them of the status of their work.

Data quality indicators are more formalized, formatted reports of data quality, for example, an annual review of specific data items indicators, such as those developed by the National Program of Cancer Registries.

In this session, we will first discuss the different types of central registry system reports and then describe the data quality indicators.

Existing Standards

- ◆ **National Program of Cancer Registries (NPCR) Standards 2007**
 - A central registry requirement
 - Specific reports determined by central registry
- ◆ **North American Association of Central Cancer Registries (NAACCR) Standards**
 - NAACCR Vol. III Standards for Completeness, Quality, Analysis, and Management of Data
 - Supported by NPCR

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In 2007 the National Program of Cancer Registries (NPCR) revised their standards and included management reports in the section on Administration as a requirement. However, the specific types of reports used are left to the discretion of the central cancer registry to meet individual needs.

The North American Association of Central Cancer Registries (NAACCR) has had standards for management reports almost since its inception, but the wording has changed over the years.

- NAACCR's standards for completeness, quality analysis , and management of data include requirements and recommendations for management reports. These are found in Standards for Cancer Registries Vol. III.

- The NAACCR Management Report standards state that central cancer registries should produce management reports with a frequency that will facilitate monitoring the operations of the registry.

- NPCR supports these standards and, in 2007, revised program standards to include management reports as a requirement.

What Are Management Reports?

- ◆ Calculations, reports, summaries, graphics
- ◆ Aggregated central registry data
- ◆ Status of surveillance system
- ◆ How well processes are working
 - How COMPLETE?
 - How TIMELY?
 - How ACCURATE?

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Management reports are documents and files based on summarized central cancer registry data that provide information on the surveillance system and its processes. Management reports will not tell you about the status of cancer in the population. These reports are used to provide information about the status and operation of the data collection and surveillance system.

The triad of registry data quality is completeness, accuracy, and timeliness. These three characteristics and others can be monitored through a variety of formatted and ad hoc calculations, printouts, summaries, and graphics generated by the central registry software and staff.

Management Reports Monitor (1)

◆ Completeness

- Status of screening of casefinding sources
- DCO rates
- Outpatient case counts
- Other estimates of completeness
 - ◆ Observed to expected
 - ◆ Incidence to mortality
 - ◆ Expected reports to observed unduplicated
- Histologically confirmed

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Management reports can monitor the status of nearly every aspect of the primary data quality characteristics, especially completeness, timeliness, and accuracy. Completeness is assurance that all items that should be included are present and there are no items present that should not be included. Management reports can monitor both case completeness and data completeness. Among the types of case completeness reports that a central registry can generate are—

- Status of screening of casefinding sources by facility, such as pathology reports, medical records disease index, and radiation therapy logs, so the central registry can monitor when these sources were last reviewed.
- Death certificate only (DCO) rates can provide an estimate of the level of completeness of cancer case registration compared to an average for central cancer registries.
- Cases identified only through outpatient sources—this helps identify potential underreporting from non-hospital sources.
- Standard surrogate measures of completeness can be calculated if the following supporting data are available:
 1. Number of cases received (observed) to number of cases expected (based on historic data).
 2. Incidence (new cases) to mortality (death certificate information from Vital Statistics needed for this ratio).
 3. Number of reports received (submissions) to observed unduplicated cases—allows assessment of if standards of case ascertainment are being met.
- The percentage of histologically confirmed cases estimates the proportion of clinically diagnosed cases and may identify incomplete casefinding at certain facilities.

Management Reports Monitor (2)

◆ Timeliness

- Submitted data
- Processing time
- Exporting of data

◆ Accuracy

- Acceptance sampling
- Edit checks
- Other

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Timeliness is the ability to make things happen on schedule. The addition of cases to the central registry database is an ongoing process that must keep moving. Management reports can monitor many central registry functions to provide status reports on the processing of cases. For example, reports may be generated that monitor the pace at which cases are abstracted and submitted, the time required to process cases, and the time required to submit cases to a national call for data.

•**Submitted Data:** The central registry can monitor the dates of diagnosis, abstracting, and submission of cases received by the registry. This allows the central registry to know whether an individual facility is abstracting cases at an even pace throughout the year and whether the individual facility is compliant with deadlines for submitting data to the central registry. Each state has its own requirements for submitting data, usually monthly or quarterly. Management reports can check that the majority of cases are submitted on time.

•**Processing Time:** As will be discussed later in this presentation, there are multiple steps to processing a case before it is added to the central registry database. Processing reports can track the amount of time a case is in each step and identify where there are delays or blockages in the processing of cases.

•**Exporting of Data:** Just as there are deadlines for receiving cases, each state registry has deadlines for submitting cases to its national database. Management reports of timeliness can track when cases are prepared, edited and ready for export to the national database.

Accuracy is the degree of conformity of a measure to a standard or true value, also described as a true representation of the facts about something. Management reports can track the overall accuracy of the database through acceptance sampling, edit check reports, and other assessments of data quality.

•**Acceptance sampling** is a statistical quality control tool that checks incoming batches of cases to determine whether they are acceptable for central registry processing. Usually an accuracy threshold is pre-set and any batch of cases that exceeds the threshold is rejected (sent back to the submitting facility for correction).

•**Edit check reports** monitor aggregate information rather than individual records. An edit check management report can identify how many cases failed a particular edit check or how many cases had single item, interfield, inter-record, or inter-database edit checks.

•**Other types of management reports** can monitor the overall accuracy of individual abstractors or facilities.

Management Reports Monitor (3)

◆ Reporting status

- By facility, county, entire coverage area
- Case counts
- Pending cases
- This year compared to last year

◆ Productivity

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As part of process monitoring, management reports can determine the status of various aspects of the data submission process. The reports can be generated by facility, county or region within a state, or on the central registry's entire coverage area. Reporting status for a facility includes if the facility is on track to report the same number of cases that the central registry expects. Among the ways that reporting status can be tracked are—

•**Case Counts:** All central registries in the U.S. have been collecting data for several years at a minimum (some for more than 70 years). Therefore, over the years, the central registries have been able to identify an estimated number of cases that each facility would report by year and by month. Case counts can be generated by month, quarter, or year from batch submissions. Comparison of the current case counts to previous years can identify problems or delays in reporting or changes in the caseload of the facility over time. Case counts are a type of process control that can be monitored graphically by tracking counts over time against upper and lower tolerances. If the case counts for a period fall below the tolerance, the central registry should investigate whether there is a problem at the facility. If there are wild swings between underreporting and what might be called overreporting (too many cases submitted for the period), the central registry should investigate whether there are staffing issues or computer problems at the facility. Naturally, the central registry quality control staff will have to apply common sense to case counts to allow for vacations, maternity leave, attendance at national conferences, or other events that might reduce abstracting time for the period.

•**Pending Cases:** Those cases in various stages of processing at the central registry. The same type of process control tracking with tolerance limits previously mentioned can be applied to central registry procedures as well.

Any type of reporting status gains extra value when the management software can store information from previous years (or months or quarters) and use it for comparison to current information.

Productivity reports how much gets done. Productivity reports in the central registry can be generated by individual or by registry function. More on this type of report later in this presentation.

Management Reports Monitor (4)

- ◆ **System status**
 - Batch monitoring
 - Backup
 - Version control

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Many types of management reports can be developed and run to monitor the status of the central registry software system. These are critical to the continuing operation of the central registry. System status reports include batch monitoring, backup processing, and version control of registry software, among other functions, most of which are beyond the scope of this presentation because they do not deal directly with data quality.

NAACCR standards Volume III lists some very specific system status management reports that any central registry software system must be able to generate. For further information on these reports, see NAACCR Standards, Volume III, Chapter 5: Data Management.

Management Report Examples (1)

- ◆ Number of tumor records reported by facility and other sources
- ◆ Differences between number of records expected and number received for each facility
- ◆ Number of cases from all sources by month and year of diagnosis
- ◆ Distribution of tumors by year of diagnosis and site

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In addition to the reports already mentioned, the NAACCR standards volume provides a number of examples of possible management reports. They are—

- A table presenting the number of tumor records reported for each reporting facility and for other sources of tumors, such as death certificate only (DCO) cases or physician-only cases. These should be reported collectively by month and year reported, or for DCO cases, by month and year of death.
- A table presenting the difference between the number of tumor records expected from each reporting facility and the number received. By ordering the table in descending order with the facility with the largest deficit on top, this report helps to allocate registry resources to the area with the greatest impact.
- A table presenting the tumors from all reporting sources by month and year of diagnosis.
- A table presenting the distribution of tumors by year of diagnosis and by site for comparison with other registries.

Management Report Examples (2)

- ◆ Number of tumors by process completed, and date received
- ◆ Interval between diagnosis date and date abstracted, and diagnosis date and date tumor record entered in central registry system, by facility
- ◆ Status of follow-up by facility and diagnosis year for central registries collecting patient follow-up

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Further ideas for management reports include—

- A table presenting the number of tumors by process completed such as number inspected or visually reviewed, or the number in suspense, by date received in the central registry to monitor workflow.
- A table showing the interval between diagnosis date and date abstracted, and diagnosis date and date tumor record was entered in the central registry system, by facility to show timeliness of abstracting and central registry processing.
- Tables showing the status of follow-up by facility and diagnosis year, and for subpopulations of interest such as specific age groups for central registries collecting patient follow-up.

Types of Management Reports

- ◆ Counts
- ◆ Calculations
- ◆ Cross tabulations
- ◆ Charts and graphs
- ◆ Comparisons
- ◆ Controls



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Basically, management reports can range from simple counts to complicated statistical analysis. They can be prepared with pencil and paper, spreadsheet software, or produced with sophisticated statistical software. In their simplest format, the reports can provide descriptive information about registry operations, such as the quantity of work moving through the registry (counts). More complex reports can compare actual counts against expected values, or cross tabulate one set of values against another. They can include calculations of summary statistics, such as percentages, means, and medians. Displaying management information in charts and graphs for visual impact is very useful. Management information can be used to trigger actions or interventions to improve system response, which is part of the quality control function.

Types of Reports

- ◆ Complete data vs. exception data
- ◆ Tables vs. graphs
- ◆ Ad hoc vs. scheduled reports



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Well-designed management reports provide tools for comprehensive management data or spotlight certain aspects of the process. For example, a monthly hospital activity report could list all hospitals and data about the submissions that month from each facility. Reporting complete data is useful, but it might obscure potential problems with individual facilities. Alternatively, a report could be designed to list only hospitals whose activities vary from the expected by a predetermined amount, such as a difference of more than 10 percent from the expected number of cases submitted. Exception reports are especially useful if there are large numbers of hospitals or activities being compared. Another variation is to produce the full report, but identify the exceptions in some way, such as with shading, highlighting, or symbols. This is analogous to the report of a blood chemistry screening panel where abnormally high or low values are flagged.

The 6 Cs of management reports can be displayed in literally hundreds of ways. Some people are more visual, while others are more numerically oriented. Tables will usually provide information in more detail, enabling complex analysis. On the other hand, graphs are often easier to understand. Graphs are better at showing a particular aspect of an issue, such as a trend or outlying value. A combination of data tables and charts can meet the styles of more people and improve understanding of the information.

Ideally, the central cancer registry should produce regularly scheduled reports of various kinds that monitor all routine steps in data collection and processing. Ad hoc reports can supplement scheduled reports when questions or problems arise. In the absence of automatically generated reports, ad hoc reports should be prepared by central registry staff on a regular basis.

Capturing Data: How and When?

- ◆ Manual: count by hand



- ◆ Computer: retrospective

- ◆ Computer: in real time, ad hoc, immediately



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Data for management reports can be captured in many ways, depending on the sophistication of the registry software. Basic registry software may contain some formatted reports, leaving other reports to be hand calculated (or not done).

If central registry software is being developed, purchased, or modified from another product, reports that have been hand calculated can be programmed as features of the new system. There is no need to continue hand calculating those reports because “we’ve always done it that way.” The users of the new system should have a say in the reports it can generate.

Manual: Count by Hand

- ◆ Slow, inaccurate
- ◆ Not flexible
- ◆ Labor-intensive
- ◆ Example: add up edit errors by item, by facility, by abstractor, for last year



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Creating management reports manually is always an option when the computer system does not have reports in place. However, preparation of manual reports is a slow, labor-intensive process, prone to errors in counting and calculations. Once a manual report is complete, the only way to revise or update it is to do another hand calculation.

Examples include—

- Counting all incoming abstracts, keeping a log, and preparing monthly summary reports by hand using a spreadsheet.
- Reviewing edit error reports for the last six months and hand tabulating the numbers of errors by item, facility, abstractor, or by any other item of interest.

Given the amount of labor needed to prepare such reports by hand, it is unlikely that a central registry relying on manual calculations could have more than occasional reports.

Computer: Retrospective Reports

- ◆ If data is available
- ◆ General purpose software
 - Fast and accurate
 - Flexible
 - Minimal labor involved
- ◆ Extract files
- ◆ Link data tables



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If the raw data such as error counts or counts of cases received for management reports are not already available from the registry software system, use a general-purpose database, spreadsheet, or statistics package to create reports.

Examples include—

- From stored edit reports on the computer, prepare counts and error rates by item by facility for the last six months (cross-tabulations).
- From the “Date Case Received” recorded on each computerized abstract, prepare frequency distributions by facility by month for the time period of interest.

If the registry software does not produce management reports of interest, extract files can be created of the necessary data to use as input to another program for generating the reports.

Other systems may allow reports to be generated through data tables used by the system “behind-the-scenes.”

Computer: Ad Hoc Reports

- ◆ Instant and accurate
- ◆ Flexible
- ◆ Minimal labor involved
 - Training in query software needed
- ◆ Provides fastest feedback



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Ideally, the central cancer registry's computer system should capture data about system operation as it performs its tasks. The system can count errors, compare values, and calculate rates and percentages. Thus, management reports can be an integral part of routine processing.

The system can also be designed to save these data in a cumulative database so that they are available for further analysis at a later date. For example, central registry staff could compare error rates in June 2006 with those of June 2005. However, if the registry software used was not designed with this feature, there may be difficulty incorporating this sort of data collection.

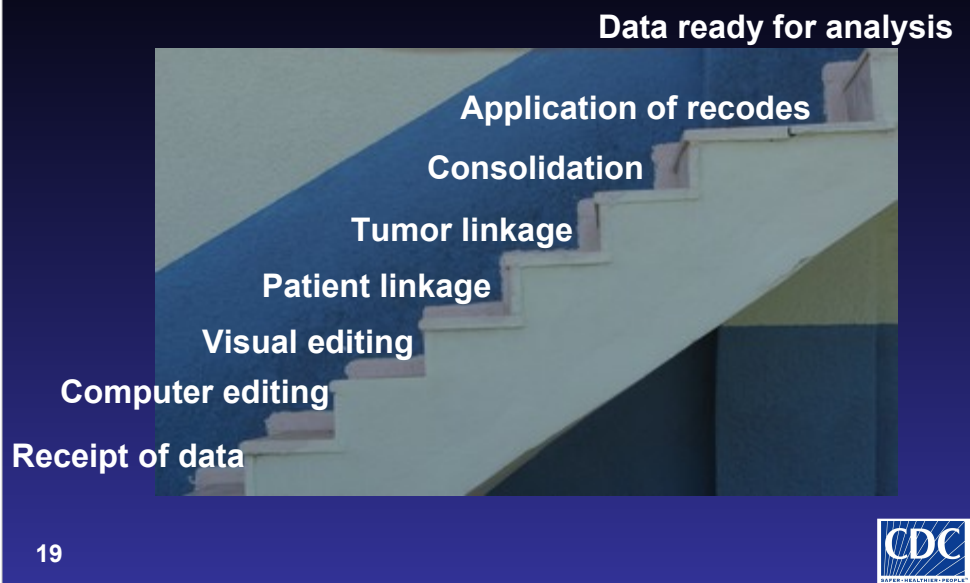
It is important to have software that can generate ad hoc or "on the fly" reports to answer specific questions that might arise. The users of the system must be able to create the reports using SQL statements, cross-tabulations, or other query mechanisms. This involves training of quality control staff on the use of the system, not just processing of data for the system.

Central Registry Process Monitoring Reports



So far we've discussed the types of reports that *should* be part of a central registry data quality monitoring system. Let us now take a look at the various processes that can be monitored using those reports.

Central Registry Data Processing



This is a representation of the steps involved in routine central registry data processing and management. The process starts with receiving raw (but hopefully edited) data from the facilities, starting at the bottom step. You take a step up when you select which data you will pay attention to, data cleanup or editing; another step when you interpret the data you selected, linkage; and another when you draw a conclusion about that information, consolidation. At each step, you take action based on your conclusions. Each step of data cleanup (editing), linkage, and consolidation contributes to the quality of the record, until your final action when the data are ready to be added to the central registry database where it can be accessed and used in data analysis, the final conclusion. The processing steps from receiving the cases through record consolidation are collectively referred to as suspense processing in this discussion, since data are often kept in a suspense file separate from the master database until these steps are completed.

At each point in the process, management reports can be useful.

Management Reports Provide Answers

- How many begin this step?
- How many finish this step?
- How long will this step take?
- Are there any bottlenecks in processing?
- Does performance differ among groups of cases?
- Is performance adequate or is intervention required?
- Can performance be modified?

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Management reports can answer the questions listed on the slide. Case counts can determine how many records start a process, how many records complete the process, and perhaps more importantly, how many records are “stuck” or hung up in a process. Time stamps at the beginning and end of a process can identify how long a particular process takes. If there are any bottlenecks in processing, a management report can qualify and quantify the problem. Performance can be measured among different groups of cases, such as those submitted by experienced or inexperienced registrars, or those edit checked at the facility compared to those submitted without edit checks. Process controls can indicate when intervention is required on the part of the central registry.

Let us look at a few types of reports useful at specific points in the suspense process.

Data Submission Reports (1)

◆ Completeness Reports

- **Number and percent of cases received by facility**
 - ◆ By month received
 - ◆ By month of diagnosis
- **Number and percent of cases received versus expected**

◆ Most basic: case counts

◆ More sophisticated: comparisons of actual counts to expected cases

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The central registry must monitor the volume of incoming cases reported from each facility on a routine basis to ensure complete and timely cancer registry data. Data submission reports can be as simple or as sophisticated as the central registry finds useful.

The most basic data submission report is a count of cases received in a specified time period. This could also be subcategorized by reporting source, diagnosis year and month, or month submitted.

More sophisticated reports could compare actual case counts (cases submitted) to the number of cases expected, based on the facility's history of data submissions.

Data Submission Reports (2)

Sample 1: Counts by Facility and Month Received State Cancer Registry, Number of Case Reports Received,* All Diagnosis Years, by Hospital and Month

	Month Received			
	Jan 2006	Feb 2006	Mar 2006	Apr 2006
Hospital X	80	63	82	0
Hospital Y	25	23	27	28
Hospital Z	0	0	50	0

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*As of September 2006



This report presents simple counts of cases **received by month**, cross tabulated by facility. Data for this table could be captured via computer reports, and individual facilities should receive a report of their own data. Data can be imported or copied into a spreadsheet. Tables and graphs can then be created by the software.

The central registry can use the report to monitor the progress of individual facilities as they report their cases. As shown in this report, Hospital Z is not transmitting cases evenly over time. Hospital X's reporting is also fluctuating, but not as much. In addition, it appears that Hospital X is late in reporting April data. However, unless we know what to expect of each facility, this information can be difficult to interpret. For example, the central registry may have negotiated with Hospital Z for quarterly rather than monthly submissions or perhaps the hospital employs a circuit riding abstractor who only visits the facility on a quarterly basis, so no cases would be expected in January and February.

Data Submission Reports (3)

Sample 2: Counts by Facility and Month *Diagnosed*

State Cancer Registry, Number of Case Reports Received,*
by Hospital, by Month of Diagnosis

Month Diagnosed

	Jan 2006	Feb 2006	Mar 2006	Apr 2006
Hospital A	10	5	8	12
Hospital B	25	23	30	28
Hospital C	120	89	53	0

23 *As of September 2006



This report shows counts of cases received **by month of diagnosis**, cross tabulated by hospital. Hospital C appears to be behind in reporting, since the counts for March and April are very low. Unless we know what to expect, though, this can also be difficult to interpret.

Data Submission Reports (4)

Sample 3: Counts by Facility and Month *Diagnosed, Compared with Expected*

State Cancer Registry, Case Reports Received, by Hospital and
Month Diagnosed, Counts and Percentages of Expected

	Month Received				Expected Qtr. 1	% of Expected Received
	Jan 2006	Feb 2006	Mar 2006	Total Rec'd Qtr. 1		
Hospital A	10	5	8	23	25	92%
Hospital B	25	23	30	78	75	104%
Hospital C	120	89	53	262	360	73%

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This report goes beyond counts to add a comparison of the number of cases received to the number expected during the first quarter. The expected number for Quarter 1 can be obtained by taking one-fourth of the total number of cases expected for the year. Alternatively, if actual numbers of the cases reported by facility are available by month or quarter from previous years, they can be used to establish the expected values.

The report also adds a calculation of the percent of expected case reports received. Combining three months of data minimizes the effect of monthly fluctuations in reporting. This calculation can be performed by the spreadsheet.

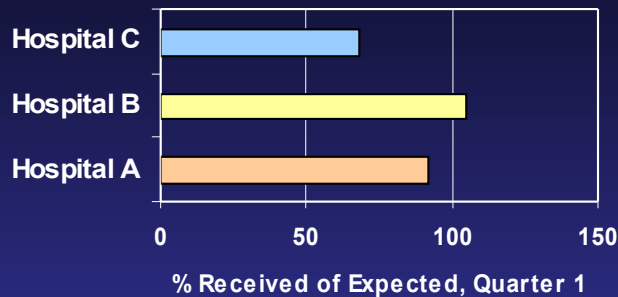
Hospital C appears to be underreporting this period, since it has reported only 73 percent of the expected caseload for the first quarter. Hospital B has reported more than the expected number of cases in the first quarter.

These types of reports should be produced and monitored on a regular basis, such as monthly or quarterly. Regular monitoring allows the central registry to address any problems in a timely manner instead of being surprised at the end of the year when completeness calculations are low.

Data Submission Reports (5)

Chart of Sample 3

State Cancer Registry, Case Reports Received by Hospital,* Percentages of Expected, Quarter 1



*As of September 2006

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This is a visual presentation of the data from the previous slide. A visual presentation can be easier to understand, especially if the central registry is comparing large numbers of hospitals. In this way, a facility reporting less than the expected number of cases can be identified immediately.

The chart's X axis goes above 100 (120) to accommodate Hospital B's value of 104 percent. Hospital B has submitted **more** cases than expected for the first quarter. If this pattern continues, the central registry may need to reevaluate the expected numbers for Hospital B. Perhaps its caseload has been historically underestimated and needs to be updated, or perhaps it opened a new cancer center in the past year and is truly seeing more patients.

Timeliness Reports (1)

Items Needed to Assess and Improve Timeliness

Data Item Name	CCR or Facility Report	Required by
Date of Diagnosis	Facility	NPCR, COC, SEER
Date of First Contact	Facility	NPCR, COC
Date Case Rpt Exported	Facility, CCR	NPCR, COC
Date Case Rpt Received	Facility, CCR	NPCR
Date Case Rpt Loaded	CCR	NPCR
Date Tumor Record Available	CCR	NPCR

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We have provided examples of management reports useful for each step of suspense processing at the central registry. Now let us take a look at some overall reports that relate to timeliness of processing along the way.

These are the data items that can be used to measure timeliness of both reporting facilities and internal case management by the central cancer registry—

- Date Case Report Exported** (as defined by NAACCR) is the date the facility exports the file to the central registry. However, this definition may vary among registries and software providers.

- Date Case Report Loaded** is defined as the date the tumor report is loaded into the central registry processing file for initiation of quality control activities.

- Date Tumor Record Available** is the date the demographic and tumor identification information on a single primary or reportable neoplasm, is available in the central registry database to be counted as an incident tumor. This is compiled from one or more source records and one or more facilities.

Timeliness Reports (2)

◆ For the central registry

- Dates reflecting central registry activity and measuring timely central registry processing
- Intervals after case is received in central registry

◆ For facilities

- Intervals reflecting facility activity
- Number and percent of cases received from the facility
- Interval between specified dates
 - ◆ By date of diagnosis or date of first contact

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For the central cancer registry, measuring the time between **Date Report Received** and **Date Tumor Record Available** measures the total time the central registry took to process the case. Using **Date of First Contact** and **Date Tumor Record Available** can measure overall timeliness of reporting, from facility through central registry.

Facility timeliness reports must be based on individual records, not on consolidated data.

Date of Diagnosis may be appropriate for class of case 0, 1, and 6, but would not be appropriate for class of cases 2 and 3 when the diagnosis is actually made at another facility. If the central registry needs to select one date field for all timeliness reports, **Date of First Contact** may be more appropriate.

Timeliness Reports ⁽¹⁾

Sample Report 1: Cases by Diagnosis Date and Date Received

■ Unusable records ■ On time records ■ Late records

		Month Received							
Month Diagnosed		Sep 03	Oct 03	Nov 03	Dec 03	Jan 04	Feb 04	Mar 04	Total
	00/00	5	2	4	2	2	5	3	23
	01/03	1	11	2	0	1	13	246	274
	02/03	0	4	1	6	0	12	149	172
	03/03	0	15	0	7	9	16	103	150
	04/03	1	10	0	6	12	14	171	214
	05/03	1	8	0	4	6	13	111	143
	06/03	2	10	1	0	0	6	122	141
	99/99	2	1	0	0	1	1	2	7
	28 Total	12	61	8	25	31	80	907	1124



This sample report is a high-level cross-tabulation of cases by date of diagnosis and date received based on reporting guidelines requiring cases to be reported to the central registry within 6 months of the date of diagnosis. The columns specify the month the cases are received at the central registry. The rows specify the month of diagnosis.

There are 30 unusable records shown in red shading, and result from an unknown or invalid date of diagnosis. (3%) This leaves 1,094 usable records. Of those, only 3% were reported on time (shown in blue shading). 33 This leaves the remaining 97% having been reported late (shown in green shading). It's obvious that this facility has a timeliness problem.

This is a simple table, but use of colors adds good visual effect.

- Unusable records (red shading, unknown or invalid date received): 30.
- Usable records: 1,094.
- On time (blue shading): 33 (3%).
- Late (green shading): 1,061 (97%).

The cases that are late can be further grouped into categories such as—

- 7 to 9 month past date of diagnosis (1 to 3 months late): 208 (19%).
- 10 to 12 months past date of diagnosis (4 to 6 months late): 445 (41%).
- 13 to 18 months past date of diagnosis (7 to 12 months late): 408 (37%).
- More than 18 months past date of diagnosis (more than 12 months late): 0.

This type of report should be provided to the administration of the reporting facility to demonstrate the seriousness of late reporting to the central registry, especially if the central registry is considering action against the facility. This same report can be generated for the entire central registry database and can provide evidence that activities to assure timeliness are effective.

Timeliness Reports (2)

Sample Report 2: Cases by number of months late by year of diagnosis

State Cancer Registry, as of 6/30/2006

Reporting Time

Accn Year	<4 mos		4-6 mos		>6 mos		Avg mos	Total cases
	#	%	#	%	#	%		
2000	64	20%	47	15%	207	15%	7.8	318
2001	314	88%	26	7%	18	5%	2.7	358
2002	313	93%	9	3%	13	4%	2.4	335
2003	335	86%	31	8%	22	6%	3.1	388
2004	210	53%	138	35%	46	12%	4.5	394
2005	113	31%	199	55%	49	14%	4.7	361

Percent Complete (2005) 91.6%

Target percent (2005) 91.7%



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Another approach to monitoring timeliness is to use a computer program to calculate the time between the **Date of First Contact** and the **Date Case Received**. Each case is marked with a lag time value and the number of cases above and below a set threshold can be reviewed easily. When the percentage of cases beyond the acceptable time lag increases to a certain point, action must be taken to reduce this number to acceptable timeliness standards.

This table lists the lag time in categories for the number of months, for the year of diagnosis.

This is another example of the type of report that should be provided to a facility to demonstrate that the central registry is closely monitoring their progress.

Computer Editing (1)

- ◆ Average number of errors per case
- ◆ Number of edits triggered
- ◆ Number of errors per edit
 - By batch
 - By facility
 - By software vendor
 - Over time

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The next process in central registry processing of data is computer editing of individual records. When the central registry captures and retains the results of computer edits, it can monitor error rates over time. This type of monitoring can be used to—

- Identify data items that are consistently problematic, so that training can be targeted to the problem area(s).
- Evaluate whether training is having an effect and improving data quality.
- Identify errors that may be consistent across cases from one vendor.
- Ensure that data quality is improving.

When vendor problems are identified, working directly with the vendor to fix the problem may be more efficient than working with each hospital user individually.

NPCR recommends that the central registry provide all reporting facilities with a copy of their state specific edit set to correct any errors before submitting data.

Computer Editing (2)

Sample Report 1: Error Summary

State Cancer Registry, Edit Error Summary, Quarter 1, 2005*

Cases

	Cases received	Number with errors	Percent with errors
Hospital A	23	3	13%
Hospital B	103	5	5%
Hospital C	262	107	41%

*As of September 2006

31



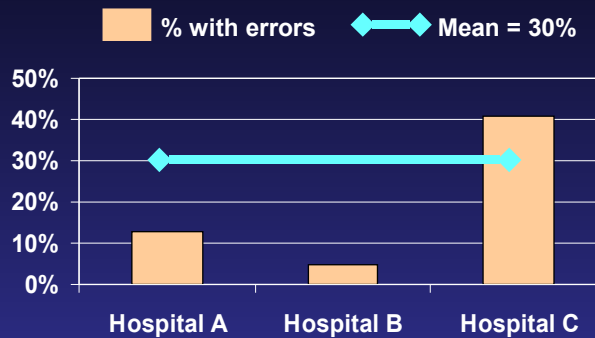
Here is a very simple report on a computer editing activity that could be produced manually. For each hospital, the table shows the number of case reports received in the first quarter along with the number and percent that had errors detected by the computer edit program.

Hospital C at 41 percent shows a high percentage of cases with errors detected. If this rate persists, the central registry needs to investigate possible causes at the facility.

Computer Editing (3)

Chart of Sample Report 1

Percent Case Reports with Edit Errors
Quarter 1, 2005, by Hospital



32



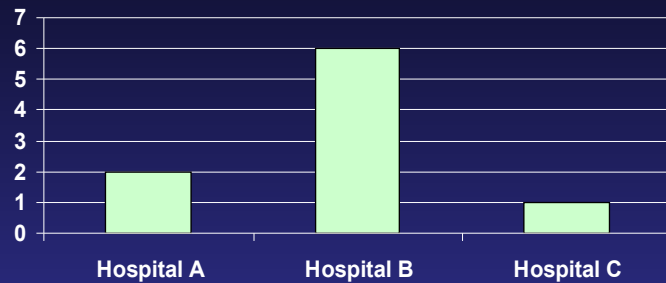
This graph shows the percentage of case reports with edit errors, using data shown in the previous slide. A graph makes it easier to identify hospitals that are better or worse than average. The mean percentage of cases with errors in this data set is 30 percent. Hospital C's percentage is below average. However, this average is skewed due to the high percentage of errors for one facility. If there is a large number of facilities, this probably would not impact the average significantly, but it would if there are a small number of facilities. In the case of a small number of facilities with one outlier, it would probably be better to use the median instead of the average. You would also want to include the total number of facilities and the range of values.

A better option is for the central registry to set a standard for errors and use the standard to measure all facilities. Also, separate reports might be generated by type of reporting facility, such as hospitals with a registry, hospitals without registries, and non-hospital sources.

Computer Editing (4)

Sample Report 2: Number of Edits with any Edit Error by Quarter by Hospital

Number of Edits with Edit Error, Quarter 1, by Hospital



33



This graph shows a different measure of data quality for each hospital, the number of specific edits that triggered at least one error, by hospital.

Ideally, each hospital would have the same edits on its computer as the central registry has in its system. The hospital would apply the edits to correct any errors before submitting data, so that no errors would be detectable by computer at the central registry. By looking at the number of specific edits that triggered any error, the central registry may identify deficiencies in the software used by the facility; for example, some edits may be missing from the software, or are not being run by the facility registry. NPCR recommends that the central registry provide all reporting facilities with a copy of their state-specific EDITS.

Computer Editing (5)

Sample Report 3: Edit Error Summary

Hospital X: 108 Cases Submitted August 22, 2005

	# of errors	% errors
Type of reporting source invalid	64	59%
Sequence number invalid	7	6%
Behavior code invalid	1	1%
Grade and histology conflict	1	1%
Sequence number, site, morphology conflict	3	3%
Site and morphology conflict	8	7%
COD and ICD code conflict	38	35%
Impossible site and morphology	1	1%
Surgery and Diagnosis confirm conflict	3	3%
Total	126	

34



This is a summary report of errors detected by computer editing of one batch of 108 cases submitted by Hospital X on August 22, 2005. This was produced by the EDITS program. The edit error report could also include a detailed listing of each case with errors (not included here).

The report shows that nine different edits found at least one error. The most frequent error was with the item “Type of Reporting Source,” with 59 percent of cases having an invalid code.

When provided to the reporting hospital, reports like this are very useful feedback.

This same report could be maintained in a spreadsheet with a column for each data submission for the diagnosis year. The central registry could then see if the reporting facility consistently fails the same edit. Maintaining separate spreadsheets for each facility in the same workbook would also allow the central registry to have a statewide total to see if there are consistencies across the state or within specific regions.

Visual Editing (1)

- ◆ Percent cases with any error vs. no error
- ◆ Percent cases requiring query to reporting facility
- ◆ Error rates
 - By data item
 - By facility
 - Over time



35



Most central registry data management systems provide an edit summary report giving the number of cases with errors and the total number of cases in the batch, as well as a separate report giving the total number of errors by edit name. The information from these reports can be entered into a spreadsheet that calculates some of the needed information. Some registries send a case to a “special” suspense file when a query is sent to the reporting facility. A check of the cases in this file would give the information needed for the second example.

If the central registry’s computer system cannot capture and calculate these data automatically, visual editing reports can be difficult and time-consuming to prepare. They require that staff keep track of errors and queries manually, then compile and present the data to central registry staff and also notify the facility that submitted the data. The central registry might consider preparing these reports on a sampling basis, such as counting all errors in a one-month period and then repeating the process at a later time for comparison.

Visual Editing (2)

Sample Report 1: Error Summary State Cancer Registry, Visual Editing Error Summary, Quarter 1, 2005*

Cases

	Cases received	Number with errors	Percent with errors
Hospital A	23	5	22%
Hospital B	103	48	47%
Hospital C	262	158	60%

*As of September 2006

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This sample is a very simple report on a visual editing activity that could be produced manually. For each hospital, the report shows the number and percent of cases received in the first quarter that had any errors detected on visual review. Even though the counts may be collected manually, the results should be recorded on a spreadsheet and therefore preserved for future review. Hospital C shows the highest percentage of cases with errors at 60 percent.

This report raises a lot of questions for a central registry quality assurance manager. All of the error percentages are very high. What error rate should be expected? What level of error is acceptable? Do these hospitals have more or fewer errors than in the past? Which data items contribute the most errors? Can the error rate be improved (reduced)?

Visual Editing (3)

Sample Report 2: Batch Summary Report Report for Hospital Y: 183 Cases Submitted February 2006

Data Item	Number with errors	Percent with errors
Address at Diagnosis	4	2%
Stage elements (CS)	38	21%
Site-specific factors	19	10%
Morphology	11	6%
Behavior	0	0%
Grade	29	16%

Comment: The grade errors all involve Gleason's grading for prostate cancers. The stage discrepancies involved several sites.



37

This is an example of a visual editing report for a single batch of cases submitted from one facility. This report should be based on a pre-determined list of data items that are to be visually reviewed. The report could also have been prepared manually. A report like this could be used by the central cancer registry to monitor the quality of work from this facility and also to identify areas where additional training might be useful. As noted by the comment, training in Gleason's grading of prostate cancer would be appropriate for Hospital Y.

When provided to the reporting facility, reports like this are useful feedback. Furthermore, feedback like this strengthens the working relationship between the central registry and reporting facilities, reducing the impression that the central registry is all “take” and not “give.”

When preparing edit error reports that are returned to the facility, it is always a good idea to include documentation or references to the appropriate rules, standards, or manuals.

Linkage and Consolidation (1)

- ◆ Total number of case reports, patients, and tumors that result
- ◆ Ratio of case reports to tumors
- ◆ Ratio of tumors to patients



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While the number of cancer cases or tumors occurring in the population is the measure of epidemiologic interest, the central registry manager also needs to assess workload. Workload is best measured by the number of case reports that must be processed by the system. Allocation of staff and computer resources relates to the number of records received in the central registry, not just the number of consolidated cases used for incidence reporting.

The ratio of case reports to tumors may change over time. Many central registries have experienced the ratio increasing with the addition of pathology reporting and as patients are seen in several diagnostic and treatment facilities for their disease. Even if the number of these cases remains the same, the workload may **increase**, because the number of records to be processed and consolidated has increased. These statistics can be useful when requesting additional resources for the central cancer registry.

Linkage and Consolidation (2)

Sample Report: Counts of Patients, Tumors, and Case Reports

State Cancer Registry, Cases Diagnosed 2005*
Number of Case Reports, Tumors, and Patients

Case reports	1,318
Tumors	1,000
Patients	950

Ratio of Case Reports to Tumors = **1.3**

*As of September 2006

This simple report shows the results of linkage and consolidation on 1,318 case reports the central registry received as of September 2006 for cancers diagnosed in 2005. One thousand tumors were represented in 950 patients. The ratio of case reports to tumors was 1.3.

As a side note, this simple report also indicates that about 5.26% of the cases diagnosed in 2005 were multiple primaries during the same year. [(1,000 tumors divided by 950 patients)-100]

Suspense Processing (1)

- ◆ Status report of cases in process
- ◆ How long does processing take?



40

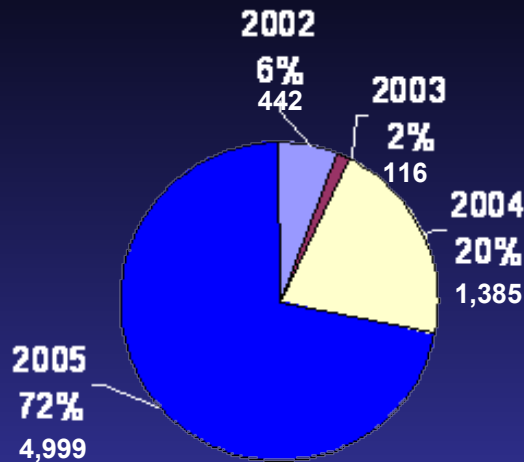


Internal quality management reports on cases in process, or suspense processing, can be very helpful in identifying processing bottlenecks by showing where cases are in the process, and how long it takes case reports to move through the system.

If this information is not available from the registry software, other manual logs using commercial spreadsheet software may have to be maintained. An example would be to keep a log of all incoming data submissions by reporting facility on a spreadsheet. When new data is submitted, the number of reports is logged in for that facility with the date received. This process can also be used to record paper pathology report submissions.

Suspense Processing (2)

Sample Report 1: Pie Chart of Suspense Cases* by Diagnosis Year



41

*As of September 2006



This is a simple pie chart illustrating the distribution of all cases in a central registry's suspense file. It shows that approximately three-fourths of the cases awaiting processing are from the current year, which is not unusual. However, more than one-fourth of the suspense cases are from earlier years, and more than 1,300 cases from 2004 are awaiting processing. Since the report was run in September 2006, the registry would most likely be concerned with completing the processing of 2004 and earlier cases, so that the data for these years could be completed and released. A report like this could be used to prioritize the work of the QC staff.

Suspense Processing (3)

Sample Report 2: Suspense Report

State Registry: Suspense Status* Report
by Diagnosis Year

	<2002	2003	2004	2005	Total
In QC	28	5	762	3493	4288
Await reply	38	2	54	102	194
In editing	99	16	378	504	937
In linkage	87	18	87	328	520
In Consol.	192	75	164	572	1003
Total	442	116	1385	4999	6942

42 *As of September 2006

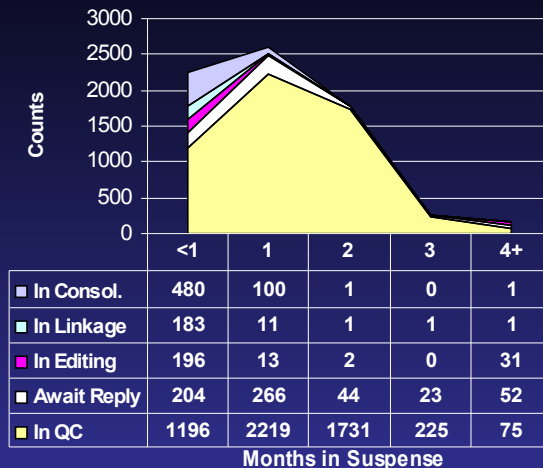


This cross-tabulation suspense report shows the status of cases in process from the previous slide in more detail, breaking down each year's cases by processing step.

Suspense Processing (4)

Sample Report 3: Suspense Aging Report

State Cancer Registry, Suspense Aging* Report



Months in Suspense

43

*As of September 2006



This is a very complex report showing how long individual cases have been awaiting processing measured in months in the suspense system. Data was collected by having the computer system date-stamp each case as it entered the suspense system, and calculate the number of months between that date and the current date. The report shows a frequency distribution of months by the processing step in which the case is waiting. Each central registry might have its own set of applicable processing steps to monitor.

The data table printed below the graph shows that 2,259 cases (1196+204+196+183+480) have been in suspense less than one month. Of these, 1,196 are in the QC process, for visual editing. A total of 160 cases have been in suspense for four or more months. The manager of the registry could use this report to identify backlogs in processing, prioritize work, and modify procedures. For example, 119 cases (44+23+52) have been in suspense for greater than one month awaiting reply from a hospital query. The central registry could decide to stop waiting and process the case "as is."

This graph was created in Microsoft® Excel.

Central Registry Completeness Reports

Sample Report 1: Total Cases Received by Site and Year

State Cancer Registry, as of 6/30/2006

Site	2005	2004	2003	2002	2001
Total all sites	17200	28264	28718	26273	26920
Breast	2997	4939	4725	4622	4763
Prostate	2172	4007	4556	4055	4192
Lung	2213	3656	3566	3385	3603
Colorectal	1806	3186	2886	3027	3072
Non-Hodgkin Lymphoma	722	1007	1574	990	979
Liver	166	275	431	204	227
Leukemia	395	707	601	565	646

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This table reports case counts by site and year. It appears that casefinding for 2005 is incomplete (17,200 cases compared to over 28,000 in previous two years).

Non-Hodgkin Lymphoma: The central cancer registry started collecting data from physician offices in 2002. Notice the increase in cases for 2002 and 2003. Then in 2004 there is a decrease. What is happening here?

Liver: Note the 2003 increase to almost two times as many cases as in previous years. What is happening in this instance?

Central Registry Completeness Reports

Sample Report 2: Percent Cases by Site and Year State Cancer Registry, as of 6/30/2006

Site	2005	2004	2003	2002	2001
Total all sites	17200	28264	28718	26273	26920
Breast	17.4%	17.4%	16.4%	18.5%	18.7%
Prostate	13.6%	14.2%	15.9%	15.4%	16.6%
Lung	12.8%	12.9%	12.4%	12.9%	13.4%
Colorectal	11.5%	11.3%	10.0%	12.5%	11.4%
Non-Hodgkin Lymphoma	4.2%	3.6%	5.5%	3.8%	3.6%
Liver	.9%	1.0%	1.5%	.8%	.8%
Leukemia	2.3%	2.9%	2.1%	2.2%	2.3%

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This table reports percentages instead of counts.

Non-Hodgkin Lymphoma: As mentioned, central cancer registry started collecting data from physician offices in 2002 and we noticed the increase in cases for 2002 and 2003. Even with the smaller numbers, this can also be seen with the change in percentages.

Liver: On the previous slide, we saw that there were almost two times as many 2003 cases as in previous years that would alert the central registry to investigate. However, because of the small number of cases, it is not so obvious when looking at percentages.

Central Registry Completeness Reports

Sample Report 3: Central Registry Unduplicated Cases Compared to National Percentages

State Cancer Registry, Comparison of Total Unduplicated Cases to National Percentages: 2003

	Breast	Prostate	Lung	Colo-rectal	Non-Hodgkin Lymphoma	Liver
State	17.3%	14.9%	12.9%	11.0%	4.1%	1.0%
NPCR	16.3%	13.5%	13.8%	11.2%	5.0%	.9%

Includes in situ and invasive cases

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This table compares the central registry's percentages by site with a national percentage to determine if the pattern seen is what might be expected. If there are any variances, the central registry might want to investigate the reason for the increase. In this case, it appears that this central registry has an elevated incidence of invasive cervical cancer.

The central registry should probably look at their cervix cases to see if there are any reporting irregularities. Perhaps the majority of these cases were identified by pathology reports only, and review of source documents indicate that coding errors were made on in situ cases.

After close internal review, if it appears the increase is real, further studies may need to be designed to determine the reason for the increase.

Central Registry Completeness Reports

Sample Report 4: Analysis of Death Certificate Follow-Back

State Cancer Registry, 2003 Cases

	# 1 st letters	# New cases	%	# 2 nd letters	# New cases	%
Hosp with registry	1000	200	20	300	50	17
Hosp no registry	800	480	60	100	50	50
Physician	1600	690	43	200	180	90
Nursing home	300	180	45			
Coroner	180	50	28			
Other	120	80	66			

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Based on 4,000 non-matched death certificate cases



This report looks at death certificate follow-back activities. Second letters are the result of a first contact identifying another facility as the source of the case. An example of this would be when a physician is contacted with a first letter and responds that the patient was seen at a specific hospital. That hospital is then contacted with the second letter. The percent represents the percent of letters sent that resulted in a new case.

This report shows where primary casefinding may not be complete. In this case, even though a large number of letters were sent to hospitals with a registry, the percent of new cases identified was fairly low even when the facility was identified by another source that resulted in a second follow-up letter. However, letters sent to hospitals without a registry identified a high percentage of cases at 60 percent for the first letters and 50 percent when the facility was identified by another source. Based on these findings, the central registry may want to provide additional training in casefinding procedures for these non-registry facilities. Further analysis may also be needed to identify specific facilities where additional training is necessary. In addition, physician reporting in this state may also need to be improved.

This report can be monitored annually to identify any changes and to identify where casefinding efforts require improvement.

Staff Management Reports

Visual Editing, Quarter 1, 2005

Staff name	Number of facilities							
Staff #1	Sm	Med	Lrg	VL	XRT	ASC	Phys	Total
	20	11	9	17	6	2	10	75
	Number of cases							
	100	500	1000	3500	50	10	25	5185
Staff #2	Number of facilities							
	10	15	24	5	7	3	15	148
	Number of cases							
	50	650	2500	1200	75	15	35	4525

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Internal central registry data management reports can also be used to distribute work assignments equitably. Tables can be created for staff with similar responsibilities, such as QC staff. These tables can be updated on a regular basis and work assignments may be changed as reporting changes. Other activities might include number of records consolidated on a daily or monthly basis.

Facility-Reporter List

- ◆ **Maintained electronically**
- ◆ **Database management**
 - **Reporter profiles**
 - ◆ **Contact information**
 - ◆ **Facility ID number**
 - ◆ **Primary contact person**
 - ◆ **Other relevant information**
 - **Update as new information is provided**
 - ◆ **Minimum of annually**
 - **Mail merge capability preferable**



49

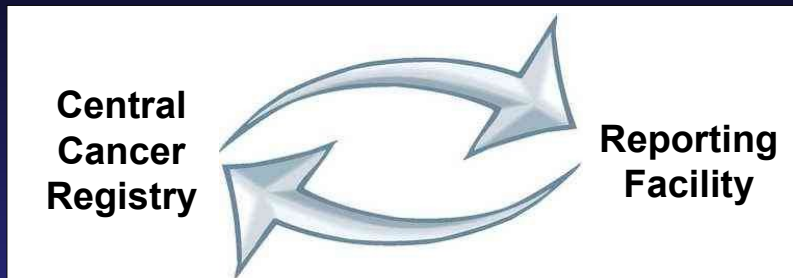


There is one more management report to consider. It is important for the central cancer registry to maintain information on all facilities and other types of reporters. Facility and physician lists can be maintained separately or together. This will be especially important with the implementation of the National Provider Identifier (NPI) numbers in 2008.

For maximum usefulness, this list should be maintained electronically, preferably in a database. The database should contain all of the needed contact information, facility identification number, name of the primary contact person, and any other relevant information for that reporter.

Information should be updated when new information is provided, such as notification of a change of address or change of primary contact person. In addition, facility and physician addresses, phone numbers, and other information should be checked and updated annually. It is very useful if the database has a mail merge function so that communication can be generated using information from the database.

Feedback to Facilities



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The central registry should generate, and provide to the facilities, a variety of routine reports including those that monitor their workflow and completeness. These reports, at a minimum, should include immediate or very rapid acknowledgement of data submissions, comparison data for facilities to use in their reports, and/or case-specific information upon request.

NAACCR Standards for Management Reports

- ◆ **Standard 5.6.3: Reports to Facilities**
 - **Standard 5.6.3.1: Reports for Monitoring Workflow and Completeness**
 - **Standard 5.6.3.2: Comparison Data**
 - **Standard 5.6.3.3: Requests for Information from Facilities and Physicians**

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NAACCR Standard 5.6.3 describes reports to facilities. This standard states the central cancer registry processing system should generate a variety of routine reports for all facilities submitting tumor records to the registry. The standard also indicates that reports can be transmitted to the facilities electronically or in paper form.

NAACCR Standard 5.6.3.1 goes on to describe the need for reports that monitor workflow and completeness to provide information to the reporting facilities about their caseload and reporting completeness. The standard suggests the need for immediate or very rapid acknowledgement by the central cancer registry that the record submission was received, including information such as the date, and number of tumor records received. This allows the facility to verify that the same number of tumor records sent were received, and that they were readable. A table presenting the number of tumor records from the facility by month and year of admission is also suggested.

Subsequent standards also address the need for central cancer registries to provide comparison data to reporting facilities for use in their annual reports, and case-specific information when requested by facilities or physicians.

Why Provide Reports to Facilities?

◆ Feedback for Quality Improvement

- Inconsistency reports
- Computer edits
- Information from case merges (consolidation)

◆ Services

- Follow-up assistance
- Comparison data



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The central cancer registry surveillance system works best when those who are preparing and submitting data are motivated to produce the most timely and complete data possible. Even when cancer reporting is mandated by law, the central cancer registry relies on the cooperation and goodwill of its reporting facilities for smooth operation and quality data. Providing data to the facilities so that the data flow becomes two-way is an effective way to build cooperation.

Management reports often serve the purpose of closing the quality improvement loop, as well as improving timeliness and accuracy of data. These include several types of reports that can be provided to facilities to improve data quality. Reports from computer edits and visual edits can be used in the central registry to correct errors in the data. Providing similar reports back to the reporting facilities allows the registrars to learn from their mistakes and prevent future errors, making future central registry procedures more efficient. Inconsistency reports also allow the registrars an opportunity to correct any errors or assumptions the central registry has made. Sometimes the central registry can introduce inaccuracies into the data during their error correction process, and the hospital registrar can review and correct the central registry's mistakes.

In preparing central registry policies and procedures for providing feedback data to reporters, there are several questions to consider. It may be most appropriate to discuss these issues with reporters before policies and procedures are decided. It would also be helpful to discuss these issues with other central registries that have implemented these types of activities successfully. The central registry can also learn from those registries who have had difficulty implementing reports...what NOT to do.

Other reports can be provided as a service to reporting facilities so that the hospitals are customers and users of the data as well as suppliers. The central registry can be of great value to hospital registries by providing follow-up information on registered cases and comparison data the hospitals can use in their own reports. Both examples help the facility meet requirements of the American College of Surgeons, Commission on Cancer.

Feedback can be provided by telephone, e-mail, in person, paper copies sent through the mail, or downloaded from the central registry's Web site. Remember, though, that confidential patient information must be transmitted using a secure method. Whatever method is used, the staff at the hospital should be informed of the central cancer registry's expectations of them, such as submitting error corrections within a specified time limit.

Assistance in Follow-Up

◆ Death Clearance

- Date and cause of death
- Death certificate file number
- Other data

◆ Shared follow-up on living patients

- Sources
 - ◆ Subsequent admissions at other facilities
 - ◆ Other linkage: motor vehicles, voter registration
- Hospital agreements

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The central registry may be able to share results of death clearance with reporting facilities by providing them with information on the death of a registered patient. In some states, release of information may be restricted by the Vital Statistics office, so the central registry must ascertain what information they are authorized to re-release to facilities.

It may also be possible to share follow-up information obtained from one source with another source that has also reported the case. This benefits the facilities by reducing the number of follow-up inquiries they must send out. The central cancer registry may also obtain follow-up from linkages it performs with other databases, such as the Motor Vehicle Department or voter registration records.

Sharing of follow-up information must be approached carefully and discussed with all facilities concerned as well as legal advisors of the central registry, since release of information may be legally restricted. It may require that participating hospitals sign agreements that specifically allow limited sharing of follow-up information with other facilities.

Comparison Data

◆ Local/state comparison data

- Site/Stage distribution
- Special tabulations
 - ◆ County/Parish
 - ◆ ZIP Code
 - ◆ Census tract
- Confidentiality concerns
- Timeliness: 1 or 2 years out of sync

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The central registry can provide valuable comparison data to facilities, such as site and stage distributions of cases for a local area or the entire state, routinely or upon request. However, expertise is required to provide the most appropriate comparison data. The reports should be prepared or reviewed by someone with statistical and epidemiological knowledge. Care must be taken to preserve the confidentiality of not only the individual patients, but individual hospitals and physicians. Hospitals receiving the data should be cautioned regarding interpretation of the results. For example, the statewide data may be one or two years older than the hospital's data, so comparisons might be from different years.

Sharing Mechanisms

- ◆ **Electronic download**
 - Accession number, medical record, sequence number
- ◆ **Paper list**
- ◆ **Copies of death certificates**

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Data or reports can be provided to reporters in different media. Paper reports can be mailed and reports can be e-mailed or accessed through the Internet. When follow-up data on individual cases are downloaded to facilities, it is essential that the data be identified accurately by numbers that the hospital uses in its database, such as the hospital's accession number and medical record number.

Copies of death certificates may be useful to the hospitals, but their distribution may be prohibited by Vital Statistics, and the central cancer registry may not have enough staff to produce copies.

Remember that confidential patient information must be transmitted using a secure method.

NPCR–CSS Data Quality Evaluation

- ◆ Data Evaluation Report
 - Standard Status Report
 - Submission Summary Report
 - Data Quality Indicators



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The National Program of Cancer Registries closely monitors data quality submitted from participating population-based registries through the NPCR–CSS Data Evaluation Report. The report displays individual data for the current submission, the previous four years, and the aggregate 5-year average.

NPCR Cancer Surveillance System

◆ Purposes

- **Receive, evaluate, and disseminate participant data**
- **Provide cancer incidence data to meet CDC's public health surveillance responsibilities**
- **Monitor progress toward NPCR goals**

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In 2000, CDC established the NPCR–Cancer Surveillance System (NPCR–CSS) to receive, evaluate, and disseminate data from registries participating in NPCR. The NPCR–CSS is designed to provide cancer incidence data to meet CDC's public health surveillance responsibilities and to help monitor progress toward NPCR goals. Beginning January 2001, registries annually report their incidence data to CDC from their reference year forward. The data are used to answer inquiries about cancer, improve planning for future health care needs, and evaluate cancer prevention and control activities.

NPCR–CSS Data Evaluation Report (DER)

- ◆ **Standard Status Report (SSR1)**
 - Quality, completeness, timeliness
- ◆ **Submission Summary Report (SSR2)**
 - Submission summary
 - Edit errors and override flags
- ◆ **Data Quality Indicators**
 - Core data
 - Advanced data

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The NPCR–CSS Data Evaluation Report is a management report generated at the time of submission of data to NPCR each January. The Data Evaluation Report consists of three parts:

1. The standard status report monitors data quality, case completeness, and timeliness of reporting by evaluating the percentage of incomplete or missing data in several demographic and cancer information fields.
2. The submission summary report provides information on the number of cases submitted for the past six years, including the number nonreportable, reportable, and invasive. In addition, the submission summary report displays tables of edit errors for core and advanced data fields and for the usage of override flags.
3. Data quality indicators are categorized into core and advanced data fields. Core data items are those required by NPCR for incidence reporting. Advanced data fields may be required by the state central registry and submitted to NPCR.

Some states require an annual case resubmission by all hospitals which allows the central registry to further evaluate completeness and “pick up” missed cases. This activity can also serve as an electronic casefinding audit. Those central registries may also produce facility-specific DERs, and recognize facilities who meet the state’s “standards.” These facility-specific DERs or DQI reports may be generated using Microsoft® Access, Microsoft Excel, or SAS.

Standard Status Report Elements

Item	12 mo. Standard	22 mo. Standard
% Completeness	90.0	95.0
Unresolved duplicates	N/A	≤ 1%
% DCO	N/A	≤ 3%
% Missing/unknown age	N/A	≤ 2%
% Missing/unknown sex	N/A	≤ 2%
% Missing/unknown race	N/A	≤ 3%
% Missing/unknown county	N/A	≤ 2%
% Passing core edits*	97.0	99.0

59 * Specific single and inter-field edits



The SSR1 evaluates data quality, completeness, and timeliness by monitoring 12- and 22-month standards for eight items. The 12- and 22-month NPCR standards are shown in the table for each of these items. These evaluations are used to determine whether the state's data meets publication standards for the annual U.S. Cancer Statistics, a joint publication between NPCR, SEER, and NAACCR.

Submission Summary Report Elements

◆ Edits Reviewed (examples)

- Race
- Primary site-morphology
- Diagnostic confirmation-sequence number
- Summary Stage 2000

◆ Overrides Reviewed (examples)

- Age/site/morphology
- Sequence number/diagnostic confirmation
- Site/laterality/sequence number
- Site/behavior
- Ill-defined site

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In addition to tracking the number of cases submitted, whether they were reportable, non-reportable, or invasive, the SSR2 report looks at specific demographic core and advanced data item edits, such as those listed. SSR2 also looks at the percentage of cases where specific edit overrides were set.

Both the SSR1 and the SSR2 review and display the results for the most current submitted data year and the previous five years so that the state central registry can monitor its own progress at reducing the number of cases with edit issues.

Data Quality Indicators (DQI)—Core

- ◆ **Demographic**
 - Birthplace
 - Birthdate
 - Hispanic Origin
 - NHIA Derived Hispanic Origin
- ◆ **Tumor**
 - Date of diagnosis
 - Topography
 - Morphology
 - Diagnostic Confirmation
 - Sequence Number
 - Grade
 - Laterality

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NPCR's Data Quality Indicators, the third part of the annual data evaluation report, are a series of data items looking at specific elements of quality in the data. The DQI are categorized into core and advanced data fields. Core data items are those required by NPCR for incidence reporting, and may affect incidence rates. Advanced data fields are required by NPCR, but do not affect incidence rates.

The DQI table displays the elements and the state's percentages for five individual years, as well as the NPCR 5-year average and comparable SEER data where it is available.

At the present time, there are no data quality standards for some of the DQI. The information in the DQI report is intended for quality review only by each central registry of its own data.

Data Quality Indicators—Advanced

- ◆ **Substate Geography**
 - County
 - Census Tract
 - Census Tract Certainty
 - Primary Payer at Diagnosis
- ◆ **First Course Treatment**
 - Rx Summ Surgery of Primary Site
 - Rx Summ Scope of Reg Lymph Node Surg
 - Rx Summ Surg Reg/Other Dist
 - Rx Summ Chemotherapy
 - Radiation Regional Rx Modality

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The advanced DQI data items provide additional detail (county and census tract), treatment information, and follow-up/survival data.

At present there are no NPCR standards for some of these DQI. They are intended for quality review by the individual states. The DQI table displays the elements and the state's percentages for five individual years, as well as the NPCR 5-year average and comparable SEER data where it is available.

Data Quality Indicators—Advanced

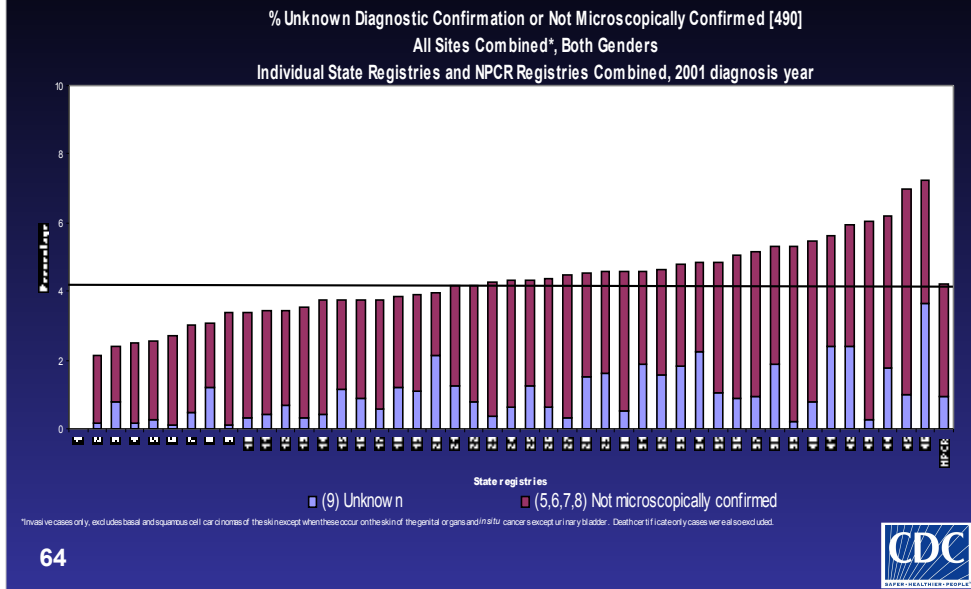
- ◆ **Vital Status and Cause of Death**
 - Vital Status
 - Date of Last Contact (decedents only)
 - Cause of Death

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The final set of advanced cancer surveillance data items can be used for survival and other outcome measures. These data represent additional examples of advanced data items that are required by NPCR and state registries.

Data Quality Indicator Results



NPCR also provides graphic displays comparing participant performance on core data items. The graph displays the percent unknown diagnostic confirmation or not microscopically confirmed for all sites combined. This includes both genders for individual state registries for the 2001 diagnosis year. At the far right is the NPCR average. The next few slides describe the NPCR averages for various data quality indicators, each of which also has a graphic display such as this one.

Data Quality Indicators—2001 Averages

◆ Percent other, ill-defined and unknown primary sites	2.48%
◆ Percent non-specific morphology (8000–8005)	3.47%
◆ Percent unknown diagnostic confirmation or not microscopically confirmed	4.23%
◆ Percent unknown or unspecified laterality (paired organs only)	6.84%
◆ Percent unknown race	1.43%
◆ Percent death certificate only	1.93%

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These are the NPCR averages for all participants for the 2001 diagnosis year. All of these items are important for accurate assessment of data completeness and quality for incidence reporting. Each central registry can compare itself against these averages to determine whether it is above or below the average.

Data Quality Indicators—2001 Averages Percent Unknown Summary Stage 2000

◆ All sites combined	9.55%
◆ Breast	4.84%
◆ Colon and rectum	8.93%
◆ Lung	12.42%
◆ Prostate	8.35%

SUMMARY

◆ Many tools to assess data quality

- Visual editing
- Process monitoring
- Audits and studies
- Management reports
 - ◆ Locally developed
 - ◆ National



◆ Use the best tool for the job

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In this session, we have provided you with a variety of examples of tools that you can use to assess the quality of your data. These include visual editing, process monitoring, audits and studies, and other types of management reports, either developed at the state central registry or provided by the National Program of Cancer Registries.

The central registry's toolkit is full. All that is needed is a little knowledge to select the best tool for the job.

When the proper tool is selected, ... [next slide]

Data Quality Is Its Own Reward



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...data quality is its own reward.

Resources

Cancer Registry Management Reports: Design and Interpretation

Original materials prepared by Jennifer E. Seiffert, MLIS, CTR and John L. Young, Jr., DrPH, CTR of the North American Association of Central Cancer Registries (NAACCR) in June 1998 under contract 200-95-0929 with the Centers for Disease Control and Prevention (CDC).

The NAACCR Education Committee had the assistance of the state registries of California, Idaho, Illinois, Kentucky, Vermont, and the Northern California Cancer Center and the Cancer Surveillance Program of Orange County, which provided examples of their experience.

Those materials were modified and updated by the staff of the National Program of Cancer Registries (NPCR) in July 2006.



The original materials for this presentation were developed by NAACCR under contract with CDC in 1998. The content was reviewed and updated by NPCR and the NPCR Central Cancer Registry Council (formerly the Logistics Committee) in 2006.

Resources

1. Dryden M and Brogan K. Quality Control. Chapter 20 in Menck H et al., *Central Cancer Registries: Design, Management and Use, second edition*. Kendall Hunt Publishing Co., 2007.
1. Ross F. Quality Control of Cancer Registry Data. Chapter 21 in Menck H et al., *Cancer Registry Management: Principles and Practice, second edition*. Kendall Hunt Publishing Co., 2004.
2. NAACCR *Standards for Cancer Registries Volume III: Standards for Completeness, Quality, Analysis, and Management of Data*, October 2004.
3. Unpublished materials provided by National Program of Cancer Registries.

The findings and conclusions in this presentation are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

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